

## HELPING CILLIAN MOVE, PLAY, AND LEARN

My son Cillian is two years old. For the first few months of his life, things seemed pretty normal. My husband and I don't have a lot of experience with babies. He is our first child, and he seemed to be doing okay.

Then, gradually we started to realize that he wasn't developing like he was "supposed to," that he was missing milestones like rolling over and crawling.



Photo Credit: Krissy Jackson

It wasn't until Cillian was four months old and hospitalized with Respiratory Syncytial Virus that we were told by the hospital's pediatric physical therapist that he might have physical issues. It began with torticollis, which is a twist in the way he held his head, but after seeing a physical therapist, we realized that there were more abnormalities than we had originally believed.

The weight of it builds over time. By the time he was 8 months old, Cillian was seeing specialists for tests and therapy every week or more. Blood tests, urine tests, MRIs, genetic tests, spinal tap. And you kind of put everything in your life on hold as you look for answers.

We finally learned that Cillian had a rare genetic disorder when he was 11 months old, but even that didn't really give us answers because the disorder affects different kids differently. Compared to kids with his specific disorder, he is significantly delayed in physical milestones.

My husband and I don't know how Cillian will develop, but what I do know is that we want more than anything to make Cillian's life as bright as possible.

As isolating as it has been for me as a mother, I know it was even more isolating for Cillian. As a baby, he was supposed to be crawling around, grabbing things, and looking at them. But he was always stuck in one place or dependent on us to move him around.

I started to wonder if some of his delays might actually be caused by the fact that he couldn't move around and learn about the world. He was stuck in a catch-22, a double-whammy, that prevented him from engaging with things and others, and his development seemed hindered as a result.

Cillian's physical therapist was the one who introduced us to the Go Baby Go! Program. It was started by a scientist who set out to study some of the same questions I found myself asking about the link between mobility and development for Cillian. It even included designs of easy-to-build robots to get children with motor disabilities moving.

With the help of a local high-school robotics team and open-source plans from Go Baby Go!, we built Cillian a car designed specifically with his disability in mind.



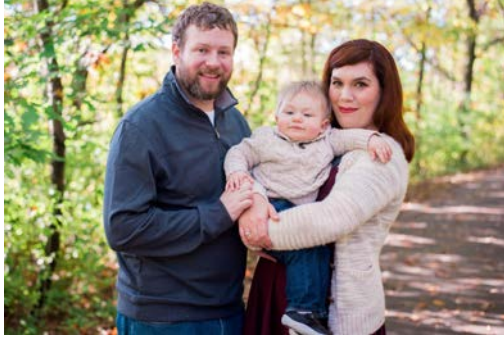


Photo Credit: Krissy Jackson

Instead of being stuck in one spot, when he is in his car, Cillian is able to zoom around our house, look at the things that he wants, and even chase the dogs.

The car has really helped his hand-eye coordination. He is clearly making real cognitive gains too. His sense of wonder and interest in the world around him has increased exponentially with the use of his car.

Living through the last few months and seeing the positive impact Go Baby Go! has had on my son, makes me want to get more involved myself. I am hoping to coordinate with the high-school to start a Minnesota chapter of Go Baby Go! so we can help improve access to these resources for other families.

-Krissy Jackson  
Farmington, Minnesota

This social and behavioral science story and the positive benefit to Cillian, his family, and others like them was made possible by research funded by the Social, Behavioral, and Economic Sciences Directorate of the National Science Foundation. The researcher, James “Cole” Galloway, studies the effects of increased mobility via robots on children’s perception, action, and cognitive development.

Today, 120 chapters of Go Baby Go! have been started in 42 states and 5 countries. These chapters have built approximately 8,000 individualized cars for children with motor disabilities. In addition, Galloway is working with hospitals, physical therapists, families, and a toy company to disseminate his work as widely as possible.

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